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These disabled people tried to play by the rules. It cost them their federal benefits

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Joseph Shapiro

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Transcript

Karen Williams (left) holds hands with her daughter, Lena Powell, while walking through St. Michael's Lutheran Churchyard in Philadelphia. Williams, who is disabled, bought a life insurance policy to pay for her funeral, but it caused her to lose access to Supplemental Security Income (SSI) benefit checks that she relies on to pay bills.

Kriston Jae Bethel for NPR

The thing that got Karen Williams into trouble was that she tried to do the responsible thing and bought a life insurance policy that would pay for her funeral.

The Philadelphia woman had seen family members scramble to find money — begging friends or starting GoFundMe campaigns — to pay the high cost of burying a loved one. Williams didn't want to burden her children.

She had no idea that buying that insurance would get her caught up in an antiquated federal rule — an "asset limit" — that snares more than 100,000 of America's poorest disabled and elderly every year, often with dire consequences.

Williams, who is disabled and doesn't work, relied upon a little-known federal assistance program — Supplemental Security Income, or SSI, run by the Social Security Administration. It sends monthly benefit checks — the average amount is $698 — to 7.4 million of the nation's neediest disabled and elderly people to help them pay for rent, food, medicine and other everyday needs.

NATIONAL

A mother has been able to care for her son with SSI. But the program also limits them

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Transcript

The program, started 51 years ago but updated little since then, is hampered by out-of-date rules, such as the limit on assets.

Williams, 63, thought her life insurance wouldn't be used until after she died. She didn't understand it had a cash value and that she could turn it in and collect $1,900. That was far less than the $10,000 in funeral expenses she bought the policy to cover when she died.

For Williams, the cash value of her policy along with the $260 she had saved in her checking account pushed her over SSI's $2,000 limit on how much a recipient is allowed in savings and other assets.

That $2,000 asset limit hasn't changed since 1989. If it had kept up over 51 years with inflation, it would be $10,000 today.

"I would have definitely went by the rules," Williams says. "I didn't know I was breaking them."

Williams did not realize there was a cash value of $1,900 for her insurance policy. That, combined with $260 in her savings, put her over the asset limit of $2,000, which kicked her off the SSI program.
Kriston Jae Bethel for NPR

The penalty was stiff: Williams was kicked off SSI, her primary source of income, and told by Social Security to pay back two years of benefits totaling $20,385.

She had 30 days to pay it back.

“The impact of it is just cruel,” says Kathleen Romig.

Romig recently went to work as a senior adviser to the commissioner of Social Security. She works on making programs like SSI fairer to children.

When NPR interviewed her last year, she wasn’t speaking for Social Security or SSI. She worked at a Washington think tank, the Center on Budget and Policy Priorities, as the director of Social Security and disability policy, where she wrote about raising SSI’s asset limit or ending it altogether.

“SSI is stuck in the past,” Romig said. “It’s hardly been changed over 50 years.”

An NPR investigation finds SSI is deeply in need of modernization.

It was intended to lift people out of poverty when it was created in 1972 and started paying benefits for the first time in 1974.

Instead, because of the asset limit and other rigid and rusty rules, SSI has become a forgotten safety net that keeps many of its recipients stuck in poverty.

NPR interviewed roughly 200 people, including those who depend upon SSI, lawyers who help them, experts who study SSI and poverty, Social Security officials, staff and others. Among our findings:

—SSI’s asset limit and other rules are so out of date that many of the poorest Americans — who most need SSI — are excluded from the program.

—Largely because of the asset limit, SSI sends out benefit checks to impoverished beneficiaries, but then often, months or years later, tells them there's been a mistake and that they need to pay back the money, which it calls "overpayments."

—SSI's asset limit and other rules impose a substantial "marriage penalty" on recipients, forcing many to skip marriage or lose benefits when they do marry.

—For many, the marriage penalty comes with even more calamitous results than losing a monthly benefit check. Many beneficiaries depend on the Medicaid eligibility that is automatic in most states for someone who qualifies for SSI, but then risk losing Medicaid if they marry.

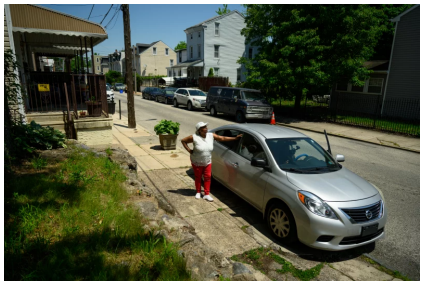
—Social Security is not up to the task of administering such a complex system. After years of budget constraints imposed by Congress, it is understaffed and hurt by an antiquated computer system and the extreme administrative burden of calculating the asset limit and other SSI rules.

A surprise in Philadelphia

In Philadelphia, Karen Williams was caught off guard when, in 2019, she got a letter from Social Security telling her she needed to come to the local office.

That's where Williams was told she was over the $2,000 limit on assets. And that she had been for a long time.

Someone at Social Security had noticed she'd accumulated the $260 in her checking account and had spotted her life insurance policy with its $1,900 cash value.



Williams was caught off guard when she was told she had 30 days to repay over $20,000 in SSI benefits because her life insurance policy put her over the asset limit.
Kriston Jae Bethel for NPR

Social Security staff knew about the policy because Williams told them about it. When someone gets approved for SSI, they give Social Security the right to check their bank accounts and monitor other records of assets.

She had purchased the policy before she went onto SSI and used her SSI benefits check to pay the premium, according to Williams and her attorneys.

At the Social Security office, Williams was told she'd been over the asset limit for the previous two years. As a result, she was issued an "overpayment" notice to pay back all the benefit checks she'd received in that time.

She owed $20,385. And she had 30 days to pay it back.

But that was impossible.

Williams was impoverished. She was disabled and didn't work. That's why she had qualified for SSI.

"You're telling me I owe you $20,000?" Williams remembers thinking in the Social Security office. "I can't even pay my bills. ... Where am I going to live?"

Social Security allows a few exceptions to what gets counted as an asset. A recipient and their immediate family living with them can own one car and a home. There are ways to put money into trusts or get waivers, but that's tricky and often requires hiring a lawyer. There's an exception for "burial insurance," but insurance for funerals often is sold as life insurance, like the policy Williams bought.

Williams said Social Security workers gave her contradictory — and even wrong — advice about how she could resolve the issue with the policy to cover her funeral expenses.

Gregory Burrell is the president and CEO of the Terry Funeral Home, located in West Philadelphia. He let Williams turn the insurance policy over to the funeral home.
Kriston Jae Bethel for NPR

Ultimately, she sought out the help of Gregory Burrell, president and CEO of the Terry Funeral Home, an institution in West Philadelphia that has served Black families for generations.

Burrell let Williams turn the policy over to the funeral home.

“We see that all the time,” Burrell, a former president of the National Funeral Directors and Morticians Association, the largest group of Black funeral directors, said of the confusion that caught Williams. “Unfortunately, people don’t know any better. And they’re stressing, and these insurance policies — they’re considered assets.”

Burrell and Williams talked about how their own parents and grandparents purchased burial insurance, putting aside small amounts — sometimes just 50 cents a month — to hand the agent who regularly knocked on the door and initialed their savings book to note the payment.

It was one of the few kinds of insurance Black families could buy, and both Burrell and Williams say seeing their parents and grandparents saving taught them the importance of financial responsibility.

A man walks past Terry Funeral Home, which has served Black families for generations in West Philadelphia.
Kriston Jae Bethel for NPR

It was deeply embarrassing for Williams when she lost her SSI checks. It was the middle of the pandemic. She got by with help from her children and friends.

She says the stress of losing her SSI check, her primary source of income, led to health problems, including two hospitalizations for heart attacks.

Williams found a lawyer at Community Legal Services of Philadelphia who helped her challenge the big bill she got from SSI.

Last year, Social Security conceded it made a mistake and had not properly told Williams of her right to appeal. Her lawyers asked for and won the agency's agreement to waive the $20,385 overpayment. But then, her lawyers say, the agency ignored its own decision and reissued the overpayment charge.

The attorneys appealed again and the order to pay is now on hold. In addition, her lawyers were able to move Williams to a different Social Security retirement program, one without an asset limit, and she started receiving benefits again.

But Williams still feels stress over not knowing whether she will still be expected to repay that money she doesn't have.

Williams smiles as her daughter, Lena Powell, holds her face while they share a coffee. When Williams lost her SSI checks, she got by with help from her children and friends.
Kriston Jae Bethel for NPR

If this sounds confusing, it is. And her case shows that SSI's asset limits and rules are so complex that not even Social Security's staff can always get things right. Recipients usually need to find an attorney to help them negotiate the process.

But attorneys are hard for poor people to afford or find. Also, few lawyers take SSI cases because Social Security puts a low cap on how much they can earn from such cases.

"It's really tiresome. I am so, so through with this," Williams says. "And I can believe that a lot of people just give up."

The worthless timeshare and the Holocaust reparations check

An average of 70,000 beneficiaries have their benefits suspended every year, according to Romig, the policy expert now at the Social Security Administration, and 40,000 have their benefits terminated.

The low asset limit, Romig says, penalizes people when they try to save.

“We know that saving is good,” she says. “We know that we can use savings to invest in things that can make people’s lives better — for example, education or safe and stable housing. We know that saving is necessary for that. And yet we’re prohibiting some of the poorest, most vulnerable people from doing just that.”

Jennifer Burdick, an attorney at Community Legal Services of Philadelphia, says the low asset limit traps people in poverty. “You need to be poor and stay poor in order to get these benefits,” she says. “It’s a disincentive against saving and being responsible in this way. It’s a disgrace.”

Burdick once represented a family that needed to fix the roof that collapsed on their house and took a small loan from a friend. Social Security counted the loan as an asset and cut off the benefits that went to the family’s disabled son.

NPR heard dozens of similar stories from SSI recipients and their lawyers, of people desperately in need of the government benefits who got kicked off or couldn’t get on because they couldn’t stay under the low asset limit.

Peter Balletti of Deer Park, N.Y., fought for years to get on SSI — after he was denied because he still owned a "worthless" timeshare in the Poconos with his ex-wife. He tried to sell it, but could find no buyers.
Joseph Shapiro/NPR

Peter Balletti of Deer Park, N.Y., fought Social Security for years after he was denied SSI benefits because he owns a timeshare in the Poconos, one that he argued is worthless.

He tried to sell it, without success, and showed proof to Social Security. One obstacle to selling it: He owns it with his ex-wife. The best he can offer a buyer is 3 ½ days of the week she uses it.

But he said Social Security staff in Long Island insisted that he needs to sell it. “That’s what I was told by my caseworker there,” Balletti says. “Because you still have the timeshare, you’re ineligible. Period. Have a nice day.”

An Illinois man, who asked to be anonymous for fear of retaliation, told us he feels trapped living in his unsafe and run-down apartment because when he saved up

for the down payment on a new place, Social Security said he was over the asset limit and moved to end his SSI.

A Holocaust survivor in Virginia received a reparations check from Germany last year, and when Social Security spotted the extra money in his bank account, it moved to end his SSI. Holocaust reparations are excluded from calculating federal benefits, but it took the intervention of an attorney to sort it out.

Stacey Ramirez's autistic son, Ryan, suddenly stopped receiving his SSI checks last year. Social Security claimed Ryan was over the asset limit, but Ramirez says the agency made an error.
Alyssa Pointer for NPR

In Georgia, Stacey Ramirez says Social Security suddenly stopped sending SSI checks to her 29-year-old autistic son, Ryan, last year. The agency, in a letter, said its review found $1,400 in two bank accounts. But Ramirez says Social Security got it wrong and there were no accounts in her son's name or Social Security number at those banks, something she says the banks confirmed to her.

Still, Social Security demanded that her son repay three months of SSI checks, a total of $2,742. Then, Ramirez says, just as mysteriously and without notice, Ryan was put back on SSI and sent three checks — for exactly $2,742. But Social Security still demanded repayment of $2,742.

Ramirez says her son was able to stay in his apartment only because his family had money to pay his rent when his income was cut off.

One irony: Ramirez and her husband, Dan Crimmins, are professional disability consultants who help other families apply for SSI benefits.

Ramirez sits with son Ryan (center) and husband Dan Crimmins. Stacey and Dan are both professional disability consultants who work with other families on applying for SSI benefits — but they had difficulty making SSI work for Ryan.
Alyssa Pointer for NPR

Social Security eventually relented after Ramirez documented months of research and calls to multiple agency staffers.

"The system is so broken," says Ramirez. "It can't support itself, much less … the people who desperately need the support."

Fifty-one years ago, an innovative approach to poverty

SSI's origins go back to Richard Nixon. In 1969, the Republican president proposed replacing the existing federal welfare system with a guaranteed basic income — of monthly vouchers — to impoverished Americans.

Nixon's plan faced opposition from many conservatives and liberals and after

three years of revisions failed to get through Congress.

But one part of Nixon's plan survived and became Supplemental Security Income, a monthly benefit to disabled, blind and elderly poor people. These were considered the "deserving poor."

SSI was an early version of what, in the last few years, has become an increasingly popular strategy for fighting poverty: to provide impoverished people with a guaranteed monthly income.

There are now some 150 of these guaranteed income experiments — sponsored mostly by philanthropies and sometimes by state or local government — that have spread across the country in just the last few years.

SSI is the "OG guaranteed income plan," says Rebecca Vallas of the nonpartisan National Academy of Social Insurance, using slang for "original gangster" to refer to SSI as the original guaranteed income program.

The new experiments show where SSI, with its many strings attached, went wrong, she says, "with all of its dehumanizing and hyper-restrictive eligibility criteria."

For most people, those monthly SSI checks provide "survival income," Vallas says. "This is money that people spend on rent. This is money that people spend on food, on co-pays on their medications, on their kids' basic needs. That's where the money goes."

Today, 7.4 million people receive those monthly SSI benefits.

Only 43% of those who apply get accepted for SSI. A Social Security Administration office determines whether an applicant meets the asset limit. A state "disability determination service" officer determines whether the person's disability is significant enough to limit work and other basic life activities.

The wait times to get approved for disability benefits are long — almost doubling during the pandemic when Social Security closed its offices. One congressional report found that some 10,000 people die every year while they wait to get on SSI or a disability program for people with work history.

Of those who collect SSI benefits, 84% are eligible because of a significant disability. There are 1 million children who receive SSI benefits. A U.S. Supreme Court ruling in 1990 expanded eligibility for children. Policy changes in 1984 expanded eligibility for people with mental illness.

In addition, a little more than 2 million impoverished people 65 or older get SSI.

As SSI expanded to include more children and people with mental illness, critics worried that the program was growing too quickly and encouraged people to depend upon federal welfare. SSI's rolls peaked a decade ago and then fell after Congress and Social Security tightened eligibility reviews — and kept the low asset limit in place.

Jack Smalligan, a senior policy fellow at the Urban Institute, says SSI serves the poorest of the poor. More than half have no other income. As a result, he says, those who get SSI gain a lot; sometimes it lifts families out of poverty.

They also have a lot to lose if they get kicked off.

Smalligan's research colleague Chantel Boyens says that for the poorest Americans, SSI can be more critical than other government assistance programs. Those may pay for food or energy bills. But "SSI is your monthly income," she says. "It's what you live on. ... 'If I lose it, do I have a roof over my head for my kids?' The stakes for SSI are very high."

One absurdity of SSI's assets limit, says Boyens, is that people lose SSI benefits when "they're still below the poverty line."

A disproportionate number of recipients are African American and Latino. Among work-age recipients of SSI, 32.8% are Black. For children, 36.8% are Black and 26.2% are Latino. People of color on SSI are even more poor than white recipients.

SSI, a $61 billion program in 2023, is funded out of general tax revenues. It is not funded by the trust funds that support better-known parts of Social Security, like the checks it sends 53 million retirees and their dependents, or Social Security Disability Insurance (SSDI), which supports 8.5 million people who leave the workforce because of a disability.

Unlike SSI's frozen rules, the amount of the monthly benefits check does change from year to year, to reflect inflation. In 2024, the maximum monthly benefit is $943 for an individual and $1,415 for a couple. The average benefit for an individual is $698.

Most states and the District of Columbia add a small supplement — an average of $145 in 2022 — to a disabled or older person's SSI check.

When SSI was created, Congress said its purpose was to "provide a positive assurance that the Nation's aged, blind, and disabled people would no longer have to subsist on below poverty level incomes."

But today, the maximum SSI check takes recipients to just 75% of the poverty line.

The asset limit was controversial from the beginning. “There seems to be a strong element of punishment associated with these tests,” an economist wrote in a review of SSI commissioned by Congress on the program’s 10th anniversary. Recipients of SSI, he said, “are required to enter into a state of pauperization with all its negative aspects.This is done as a punishment for having to seek help from the rest of society and as a warning (and hence deterrent) to others.”

Katie Savin, an assistant professor of social work at California State University, Sacramento, says now SSI’s stalled asset limit adds to that stigma. “People must limit their own opportunities for work and marriage, submit to continuous surveillance of their finances, health and personal affairs and survive on poverty-level income without ever having more than $2,000 in assets,” Savin says.

Till Social Security do us part

Last year, Gabriella Garbero of St. Louis passed the bar. She opened her own law firm, but quickly had to stop taking paying clients.

“I really had to limit what I was doing and I haven’t taken on any new cases because I’m really afraid,” she says.

Gabriella Garbero poses for a portrait outside her home. She received her law degree from Saint Louis University School of Law and passed the bar in 2023. But she has not been able to take on new clients because it will likely put her over the SSI asset limit.

Neeta Satam for NPR

She's afraid of something that other lawyers don't have to worry about: that she'll make too much money.

Which, in her case, means just $2,000 — the SSI asset limit.

Garbero was born with spinal muscular atrophy, a condition that causes weakened muscles.

Nurses come to Garbero's home, 12 hours every day. Personal care assistants are scheduled, when she can find them, several hours more.

"I'm not able to do any of my own care. So brushing my teeth, washing my face, give me a shower," she says. "Just all the basics that you physically do for yourself."

Most importantly, she requires nurses and aides to run and monitor the technology that keeps her healthy and out of the hospital or a nursing home.

There's her feeding tube and the ventilator that keeps her breathing at night.

She needs a nurse to operate the machine that suctions her lungs, several times a day.

Without that assistance, "I would just be dead," says Garbero. "There's not really another way I could function."

But it's all tied to SSI.

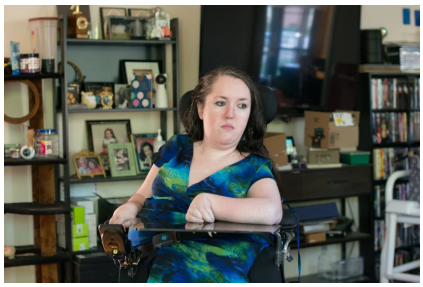
In most states, someone who is eligible for SSI is automatically qualified for Medicaid, the state and federal health insurance for people with little income.

It's Medicaid that pays for Garbero's nurses and aides. Private insurance, the kind that people get through work, typically won't cover in-home personal care assistants and nurses.

Garbero's only other option would be to make enough money to pay for her aides and nurses out of her own pocket. But the cost for the level of assistance she gets, Garbero calculates, would run between $100,000 and $200,000 a year. She doubts she could make that much.

So to keep her SSI and the Medicaid that's tied to it, Garbero is required to stay under the $2,000 asset limit.

Garbero is 33. She was born six months after President George H.W. Bush signed the Americans with Disabilities Act into law in 1990, proclaiming: "Let the shameful wall of exclusion finally come tumbling down."



Garbero has spinal muscular atrophy and requires nurses and aides for everyday care. She needs to maintain her SSI benefits in order to qualify for Medicaid, which pays for the care that keeps her healthy and out of the hospital or a nursing home.
Neeta Satam for NPR

When SSI was created in 1972, there were very different — and much lower — expectations for the lives of disabled people.

SSI, for example, predates the law passed in 1975 that first gave disabled people the right to go to school and get an education. Before then, more than 1 million disabled children were excluded from schools.

SSI came years before the ADA, which banned discrimination at work, on public transportation or access to public places like going to restaurants and movie theaters.

"We have made a lot of progress over the last 50 years as disabled people," Garbero says. "We went from being mostly institutionalized, not going to school … not going to public places."

Still, there's one basic right that Garbero misses — solely because she needs SSI.

She can't marry, without substantial risk.

It is difficult for someone who gets an SSI check to marry and stay under the asset limit — because a spouse's income is counted.

Where a single person on SSI is allowed up to $2,000 in assets, the limit for a couple is only $3,000.

That's another limit that hasn't budged since 1989. (Both asset limits, for individuals and couples, were raised by Congress in 1984 — from $1,500 for an individual and $2,250 for a couple — but the new levels didn't take effect until

1989.)

NPR interviewed dozens of people who said their only options were to marry and lose SSI, marry and then lie about their relationship, or to close themselves off from a romantic relationship altogether.

Garbero has been involved with her partner, Juan Johnson, for several years — but they can't make plans to marry.

She'd like that commitment. Plus, she grew up in a religious family where marriage is important.

Several years ago, Garbero says her caseworker at Social Security "asked if we were sharing a bedroom."

Garbero ducked the question. "My heart was pounding when she asked that because I didn't know if I was about to get in trouble," she says.

The caseworker dropped the issue. But Garbero says she realized the government worker "had all the power over my life that she could ever want."

Garbero looks at her partner, Juan Johnson, outside their home. The two would like to get married, but their combined income would exceed the SSI $3,000 asset limit for a couple. The limit has not changed since 1989.
Neeta Satam for NPR

Under Social Security's rules, a couple doesn't need to be legally married for a disabled person to lose SSI. Just living as if they're married, called "holding out," is enough to get counted as a couple under the $3,000 asset limit.

One woman, who asked to stay anonymous, told NPR she married but then divorced her husband to stay on SSI. Currently, the man doesn't work and does a lot of her caregiving. They still spend most of the time together, but they keep separate apartments. When the woman's state caseworker comes for a visit, she says she takes down all the photographs of her with her partner.

Social Security said it could not provide data of how many people lose SSI for violating the "holding out" rule or for marrying. NPR could not find recent examples of people who lost their SSI for living as a couple, but found dozens of

disabled people who hide relationships or say they avoid them altogether.

“Nobody should be afraid to say they’re in a relationship with somebody,” says Garbero, comparing the situation to the fight for the legalization of interracial marriage in 1967 and marriage for same-sex couples in 2015.

In law school, Garbero wrote a law review article about SSI’s so-called marriage penalty. “The choice disabled people must make is always simple: it is a choice between marital happiness and medical necessity,” she concluded.

“The American Dream is supposed to be open to everyone, regardless of status, and achieving it includes having a fully formed family to come home to at the end of the day.”

A 50% tax and when kindness creates risk

SSI’s low asset limit is the most common cause of overpayments, says Romig.

Social Security reported $4.6 billion in overpayments in fiscal year 2023.

Martin O’Malley, the new commissioner of Social Security, revealed the extent of those overpayments when he told a congressional committee in March that 1.3 million people — 1 out of every 6 people who rely upon SSI — got an overpayment notice last year.

Often, he said, they and others on various Social Security programs get charged an overpayment for “no fault of their own” and that the agency uses “brutal” methods to get the money back.

In March, O’Malley announced some preliminary steps to make it easier for people to challenge SSI overpayments. The burden of proof will now fall on Social Security, not the recipient, to prove that the person who gets the check did something to go over the asset limit or to cause the overpayment. And those who owe money can work out a longer repayment plan.

O’Malley, at a conference on SSI this month, called on Congress to raise SSI’s asset limit.

Former Maryland Gov. Martin O'Malley, the current commissioner of Social Security, testified during his confirmation hearing on Nov. 2, 2023. He says Congress needs to increase the SSI asset limit.
Kevin Dietsch/Getty Images

Still, Social Security so frequently recalculates a recipient's financial eligibility — sometimes monthly — that it's dangerous to save and easy to run afoul of the low asset limit.

By regulation, an eligibility review is done every one to six years, but also when a beneficiary's income changes — often when someone works or receives financial support, as simple as groceries or a place to live, from family or a friend.

If someone on SSI works — almost always, it's part time — they're allowed to earn no more than $65 a month before the monthly benefit check is reduced. That limit hasn't changed since SSI started in 1972.

On earnings more than $65, Social Security will reduce their benefits by $1 for every $2 they make.

When SSI was created in 1972, few people with significant disabilities worked. But

that has changed.

In 2008, Bill Morris, who runs a recycling company in Colorado, saw men with autism and other developmental disabilities skillfully taking apart electronic devices. They were members of a volunteer work program. Morris started hiring them at minimum wage or above. He says he found workers who did their jobs well and rarely missed a day of work.

Most of these disabled workers need SSI. It gets them onto Medicaid and it pays for their group homes or other living arrangements.

But they're constantly in danger of going over the $2,000 asset limit, which hasn't kept up, especially as the minimum wage rises. So Morris ends up needing to cut the work hours of his employees at Blue Star Recyclers — even though he needs them and when they want to work more.

Morris complains about the outdated asset limit and how SSI is run by Social Security. "They're hurting the very people they're supposed to be advocating for," he says.

Those whose income changes — including those in part-time work whose pay and hours differ from month to month — are required to report each month's earnings, providing pay stubs and receipts.

The process is difficult and bureaucratic, and that makes mistakes common, says David Camp of the National Organization of Social Security Claimants' Representatives. Often it requires mailing documents or taking them to a Social Security office monthly. And then getting mail back. Lawyers who represent beneficiaries get "a bucket of mail a day, literally, a bucket" from Social Security, says Camp.

Someone at the agency, which is understaffed after years of budget cuts and staff attrition, often needs to take those receipts and pay stubs and type the information into a case file.

Then someone calculates benefits using a complex, 30-step worksheet.

The kindness of family and friends can put someone's SSI benefits at risk — often in bizarre ways, says Debora Wagner, an attorney who studies overpayments at

Cornell University's K. Lisa Yang and Hock E. Tan Institute on Employment and Disability.

If a disabled person on SSI lives with family rent-free or for less than market rate, that counts as income. Social Security collects data on the family's rent and living costs to calculate the SSI beneficiary's "fair share" of rent.

If they're not paying that, then their SSI benefits are reduced by a third.

An even more burdensome rule will end in September: the requirement that someone who gets an SSI check needs to report every month if anyone — including a parent or a friend — paid for their food, gave them groceries, invited them home for Thanksgiving dinner, or took them out for a meal to celebrate their birthday.

That, too, if over $20, counted as income and got deducted from their monthly benefit checks.

Until September, SSI recipients are still expected to provide Social Security with the receipts that show the amount of any food — from a grocery store or restaurant — that was gifted to them.

Restrictions on other gifts will remain in place. If a parent gives their disabled daughter $100 "to help them make ends meet," Wagner notes that Social Security "would reduce her SSI by $80. She would only get to keep $20 of that."

When people go over the $2,000 asset limit, sometimes they get a warning from Social Security to quickly, within days, "spend down" money they've saved. This is common when people work. Wagner tells them "to go to a warehouse store and buy and stock up on paper products and canned goods and frozen foods that are not perishable that they can keep for a while" — items that aren't counted against the asset limit.

Wagner says SSI's byzantine rules are particularly puzzling to families seeking to support young adult children with disabilities. "I encounter a lot of families who are middle income families who've never had to deal with a poverty program like SSI," the attorney says. "It's a completely foreign concept to them that giving gifts, doing kind things for people that they love are actually going to create problems" — like putting someone over the asset limit and getting them charged for

overpayments.

“The thing I hear from families all the time is ‘I just wanted to help.’ Well, of course they do. But SSI penalizes people for being helped.”

The extreme red tape of SSI isn’t just a problem for recipients and their families — it’s a burden for Social Security, too.

It costs Social Security a lot of money to do all those complex calculations. O’Malley, at a conference this month, said SSI accounts for just 4% of all the benefits Social Security gives out, but it takes up 38% of the agency’s administrative budget.

Overpayments and fear

Valerie Smith noticed right away when Social Security, two years ago, deposited an extra SSI check in her son’s bank account.

Smith paid a friend to drive her to a nearby liquor store, where she paid for two cashier’s checks for $841 (the amount of the extra check) and then to take her to the local Social Security field office.

Valerie Smith is a full-time caretaker for her son, Courteze Goods, 29, who has spina bifida.
Rosem Morton for NPR

There, she handed the money orders to a staffer and got two receipts in return.

But today, Social Security says it has no record of the returned check, even after she called and returned to the office and showed the receipts that were written to her.

“They just keep sending me threatening notices saying that I didn't pay the money back,” says Smith. “And now they’re taking money out of my son’s check.”

That’s $120 a month, from the money Smith and her son, Courteze Goods, need to survive.

The monthly SSI check allowed Smith and Goods, who was born with spina bifida

and is 29 now, to buy food, pay for medical supplies not covered by insurance and to pay the rent on a subsidized townhouse in Baltimore with a ramp for his wheelchair.

Smith brings food to Goods. She noticed right away when, two years ago, Social Security sent her son an extra SSI check. Right away, she went to the Social Security office, returned the money and got receipts. But now the agency says she still owes the money.
Rosem Morton for NPR

It wasn't the first time Social Security demanded that Smith pay back money. In 2011, someone at Social Security noticed that a child support payment from her son's father hadn't been properly recorded — back in 2006.

Because Social Security hadn't adjusted her son's monthly benefits, based on the new child support amount, the agency ruled that Goods had received too much.

It took Social Security more than five years to notice the mistake. It then sent Smith a bill for an "overpayment" for all those years of checks. The letter was a shock. She owed $24,685.19.

"My heart started beating," she says. She worried whether she was "going to get locked up" or was Social Security "going to take my son's check away?"

Smith's nearby Social Security office in Baltimore is currently closed for renovations.
Rosem Morton for NPR

Smith is a careful recordkeeper. Her bank now automatically sends Social Security records of every child support payment. But before it did, Smith faithfully sent copies. At her townhouse, she pulls out a tall stack of envelopes with the proof.

When Smith got the overpayment bill, she appealed. It wasn't her mistake that her son's account creeped over the asset limit, she said. And she didn't have the money to pay back years of benefits.

Once she filed the appeal, Social Security was required to stop taking money from her son's check. But it still deducted thousands of dollars. Her attorney, Victoria Robinson of Maryland Legal Aid, has asked the agency to return that money, but

the family is still waiting.

In 2022, the attorney helped move Goods to a different Social Security program that is not means-tested.

With Social Security benefits, Smith and Goods can live together in a Baltimore townhouse, with a ramp for his wheelchair, and go to church, where Goods is a deacon.
Rosem Morton for NPR

When Smith's son was born, she quit her job to care for him and make sure he could live at home, go to school and to church (where he's a deacon) and live a regular life.

Because she stopped getting a paycheck when she became a caregiver, she didn't work long enough to qualify for Social Security retirement or disability income.

The caregiving is often rewarding, but it's sometimes hard, physical work, with lifting and pulling. When Goods was young, there were times when — after hip and knee replacement surgeries — he'd be in a heavy full-body cast.

They lived on a second floor then.

"I would have to carry him up the steps," Smith says. "Sixteen steps, and bring him down 16 steps."

Smith shows a poster board with photos of Goods during his childhood.
Rosem Morton for NPR

Now after decades of caregiving, Smith, who is 59, deals with her own disabilities. Dislocated discs in her back, hernias, high blood pressure, a stroke and more. "I might not look like I have it but I have it," she says with a laugh. "And it's only because of God causing me to look the way I look on the outside."

A year ago, Smith qualified for SSI for herself and now those benefit checks keep her going as she continues to take care of her disabled son.

Letting down the public

It's not just SSI beneficiaries, their families and lawyers who have a hard time figuring out the rules. They frustrate Social Security staff, too.

"Personally, I feel like I'm letting down the public," says Roy Porter, a claims expert in upstate New York. "Just the amount of time it takes to actually get the work done on top of having these outdated regulations. It's overwhelming."

"These days, $2,000 doesn't get you too much," says Porter, who adds that he and other Social Security staffers agree that the asset limit should be raised. "People can't save that money to pay their basic expenses."

Workers NPR spoke to said they take pride in being able to help disabled and elderly people on SSI. "They have no income, nothing," says Stephanie Rodriguez, a claims representative in California. Her job is most rewarding, she says, when she can help people "when they're at their lowest" to get funding to help them stay housed and to pay for food and medicine.

But the Social Security workers talked about burnout levels of stress that result from SSI's outdated rules and asset limit. They spoke of growing workloads and pressure from managers to spend less time with recipients with problems. Most know a colleague who quit because of the stress.

The staffers speak, too, of the stress of sometimes confrontational interactions with angry SSI recipients. Many of them complain about bureaucracy, overpayments and the long wait times trying to get through when they call the agency's 1-800 number.

"The stress that the workers feel is nothing probably compared to the stress that the American public feels as they're waiting for these SSI disability decisions to come to stabilize their income," says Jessica LaPointe, president of the American Federation of Government Employees Council 220, which represents field office workers.

Social Security Commissioner O'Malley acknowledges many of his staff's complaints and has cited high staff turnover and low morale as problems to address. He says Congress needs to increase funding to the agency. "We have more customers than ever with fewer staff than in 25 years," he says.

O'Malley says his agency also needs more money to update an antiquated

computer system that uses programs from SSI's origins, creating problems for workers and beneficiaries.

Steven Kraidman has been battling with Social Security for years to get an answer on how much he may owe for past SSI overpayments.
Joseph Shapiro/NPR

Crysti Farra, a Long Island attorney, says a frustrated Social Security staffer blamed computers that don't connect from office to office for why her client, Steven Kraidman, can't get a clear answer on how much he may owe for past SSI overpayments. His bill changes month to month, from $937 to $12,552 to $29,660, then lower or higher.

"As you get older, you don't want to feel helpless," says Kraidman, fed up with his years-long battle with the agency and its creaky computers. "If this is the golden years, let it not be filled with lead."

The search for solutions

There's one thing that most people — from Social Security staff to scholars, from lawyers to lawmakers — agree would solve many of SSI's problems: raising the $2,000 asset limit.

Last September, a bipartisan group of lawmakers introduced the SSI Savings Penalty Elimination Act, which would raise the asset limit from $2,000 to $10,000 and from $3,000 to $20,000 for a married couple. That would bring the limits more in line with what they would be if they had kept up with inflation. The legislation also includes annual future raises for inflation.

"We shouldn't be trapping elderly or disabled Americans in poverty by punishing them if they do the right thing, if they try to set aside a little bit of money for savings." said Sen. Sherrod Brown, a Democrat from Ohio and the bill's co-author. "It should be common sense."

Democratic Sen. Sherrod Brown of Ohio (left) and Republican Sen. Bill

Sen. Bill Cassidy, a co-author and Louisiana Republican, worried that the current asset limit keeps people from trying to work. "It's an easy fix, encourages work, allows savings and gets people out of poverty," he said. "What's not to like?"

The bill has stalled in Congress.

Cassidy of Louisiana (in back) listen to Emily Demko and her mother, Margaret Demko, outside the U.S. Capitol last summer during a press conference on reforming the SSI program.
Megan Smith/USA Today Network via Reuters

One issue is cost. Social Security's actuaries estimate that raising the asset limit to $10,000 would add $9.8 billion to the program over 10 years, in part because more people would be eligible.

Romig, the SSI policy expert, calls these costs "modest" since updating the asset limit would make the system more efficient. Fewer recipients would get kicked off SSI and Social Security staff would spend less time needing to do complex monthly calculations.

In addition, SSI would reach more people and more would become eligible for Medicaid as a result.

Almost any solution would need to come from Congress. Smalligan, the Urban Institute researcher, supports raising the asset limit. Meanwhile, he says Congress or Social Security could change the way it determines who is over the limit. Instead of checking whenever someone's income changes, even monthly, the agency could certify people for a year at a time "and let them keep their benefit until they're recertified."

Vallas, with the National Academy of Social Insurance, notes that almost every state has reformed or eliminated asset limits for other income assistance programs such as food stamps, welfare or energy assistance. That change, she says, reflects an understanding among poverty experts that such limits are antiquated and often keep people in poverty.

Vallas asks: "And yet, which program has been completely left out from that policy trend? SSI. Mostly because almost since its origins, it's just always been the forgotten safety net."

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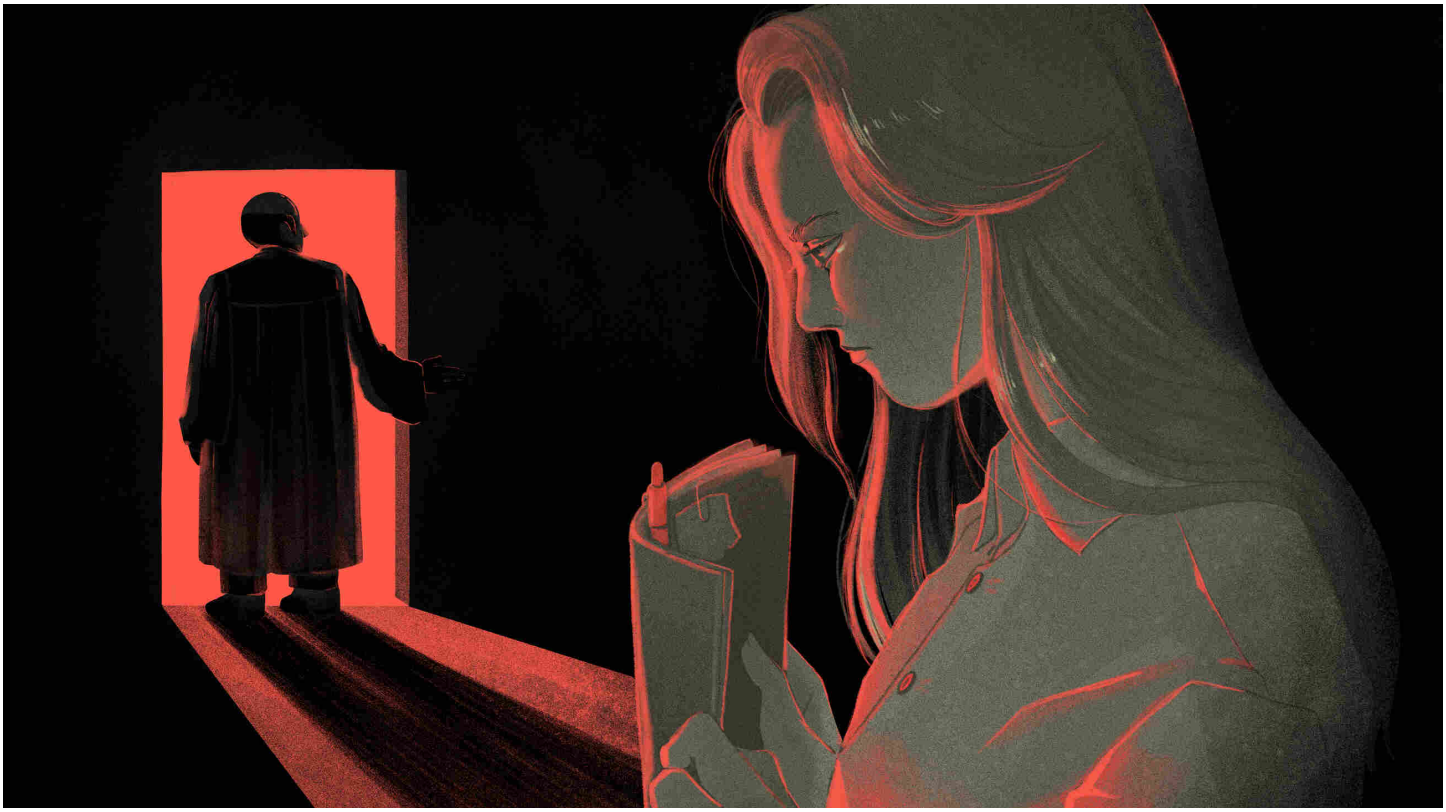

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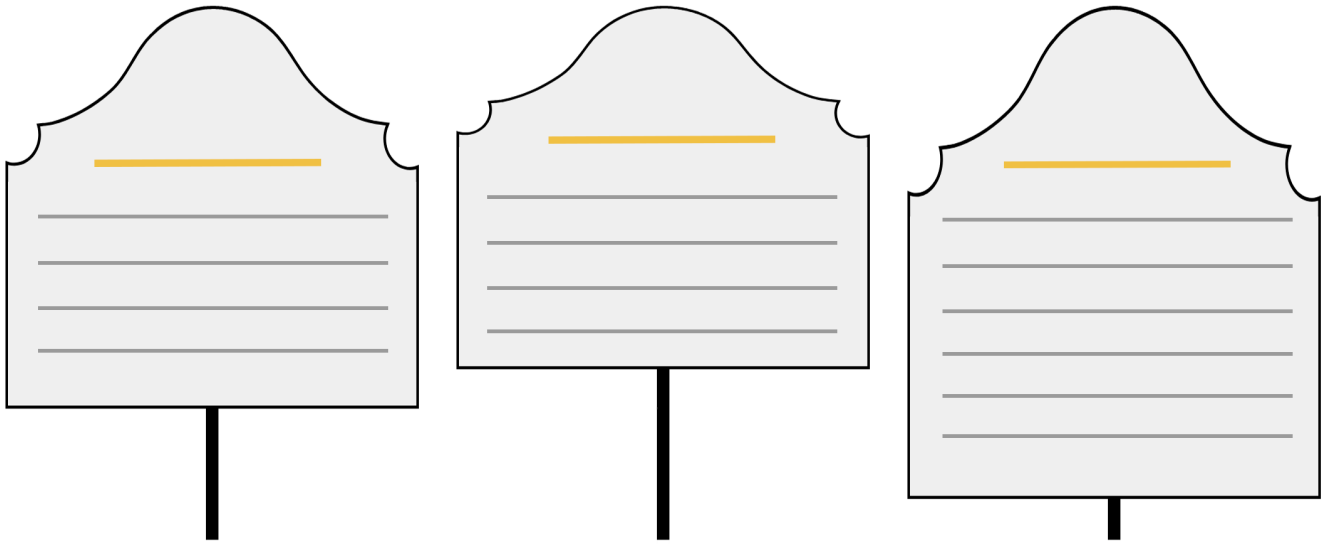

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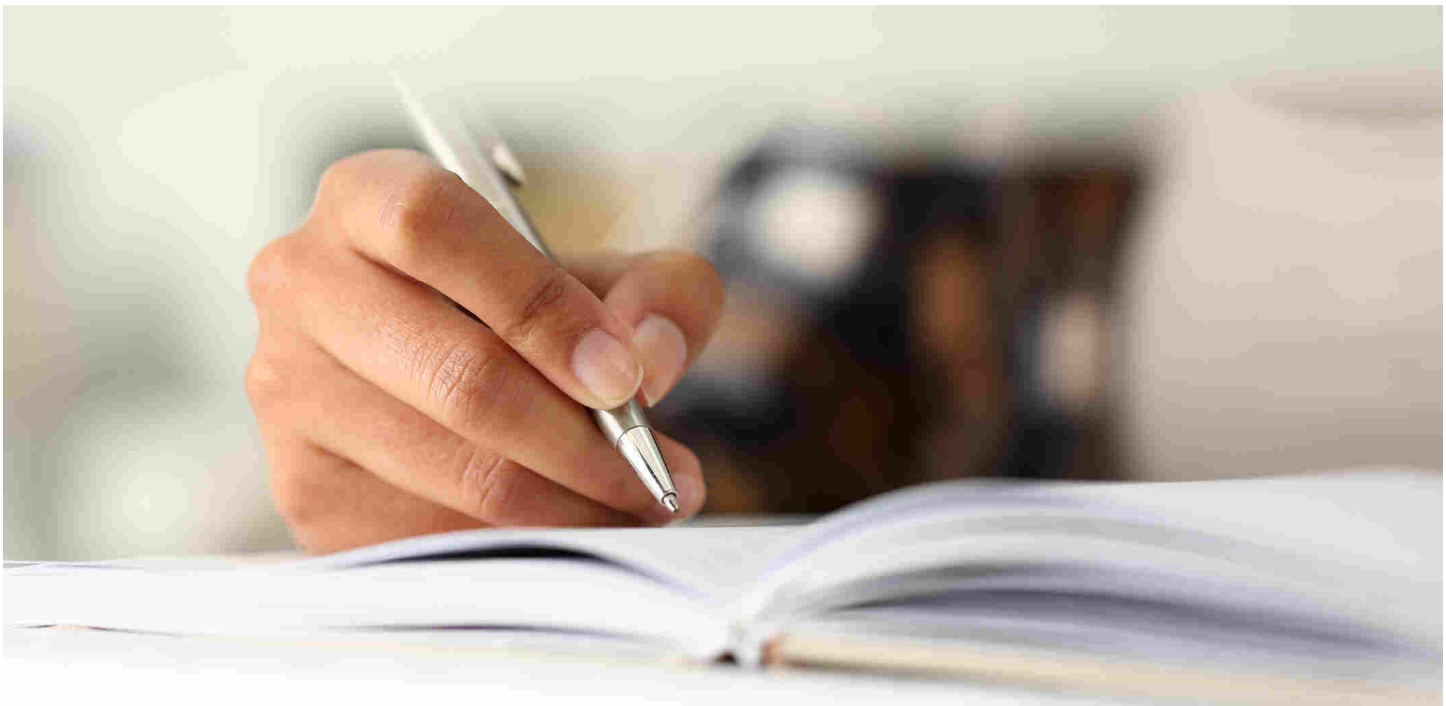

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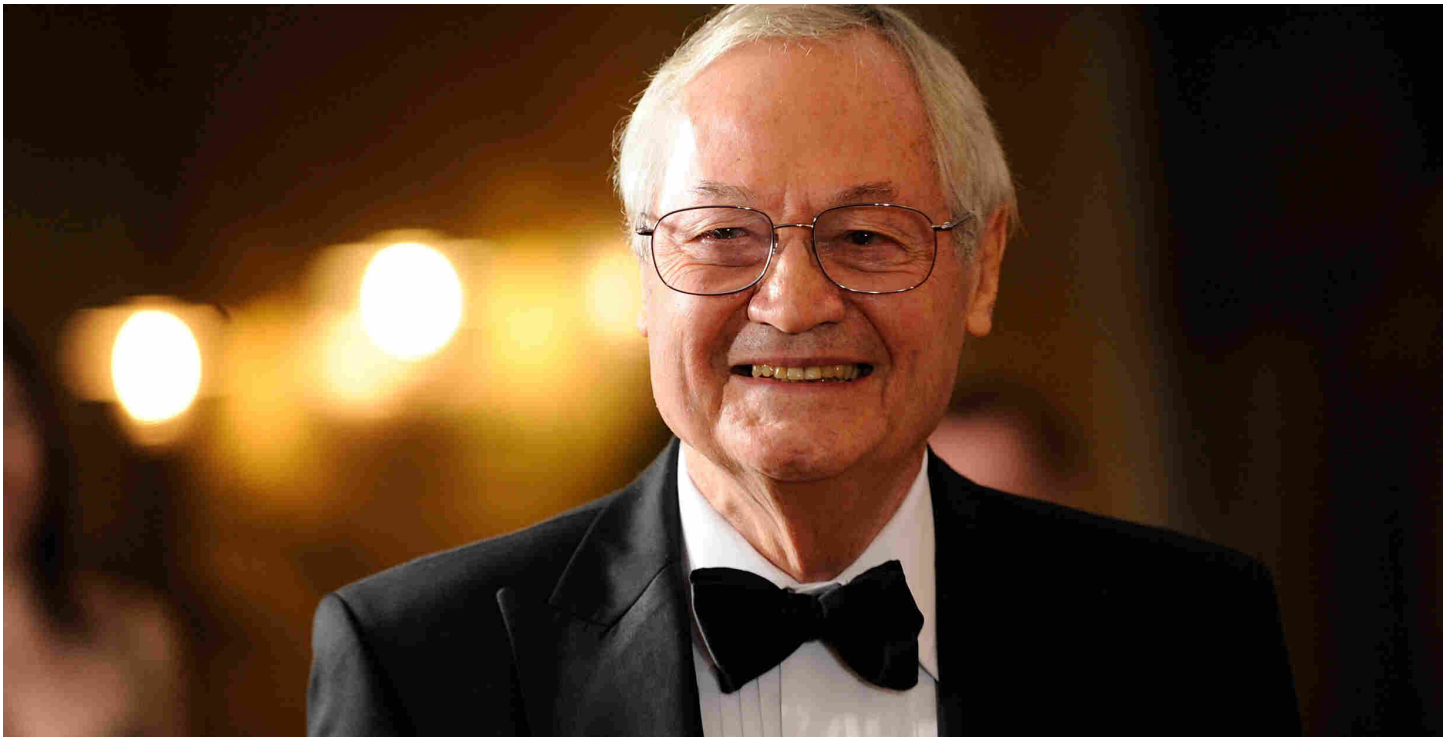

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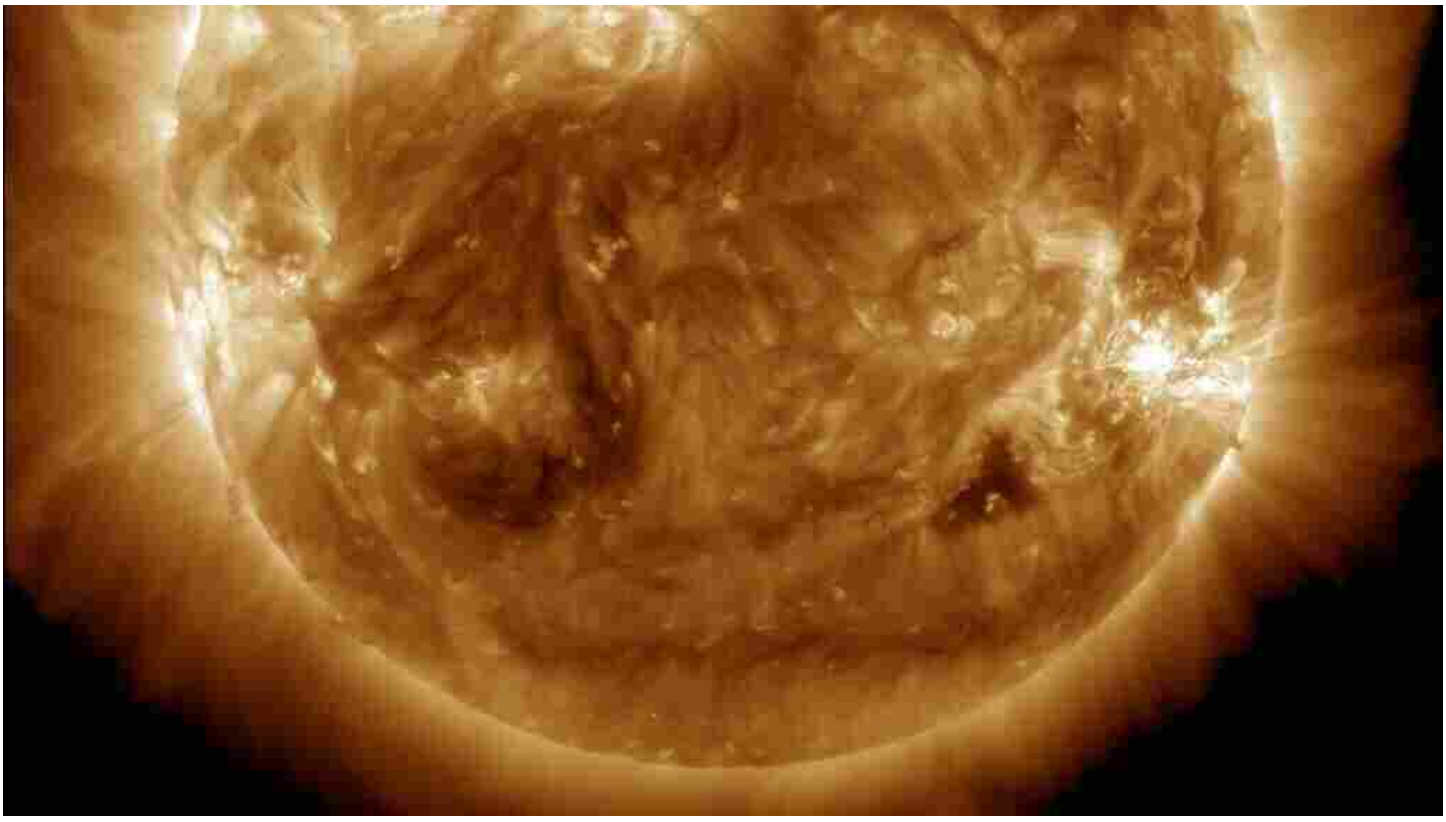

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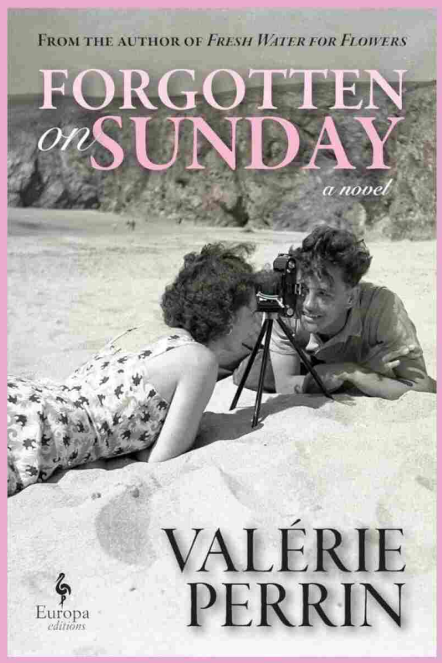

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